

# SWISS BIOBANKING PLATFORM TERMS OF USE



## 1. SCOPE

These terms of use (**ToU**) apply to the digital solutions (**Solutions**) provided by the Swiss Biobanking Platform association, route de la Corniche 3A, Bâtiment Phényl, 1066 Epalinges, Switzerland (**we**, **our** or **SBP**), including our website accessible at <https://swissbiobanking.ch/> (the **Website**), the Solution for Quality Assessment and Normalization (**SQAN**) available at <https://www.biobanksqan.ch/> (**Biobank SQAN**), and the Network Exploration Tool (**NExT**) platform accessible at <https://ecat-biobank.sib.swiss/search> (the **NExT Platform**), and any services we provide through them (together with the provision of the Solutions, the **Services**).

## 2. TERMS OF ACCESS

### 2.1. ToU Acceptance

Any access to, and use of, the Services, or any content available on them (the **Content**), are subject to acceptance of these ToU. Anyone who accesses and/or uses the Services and/or the Content (a **User** or **you**) acknowledges having read, understood and agreed to these ToU.

### 2.2. Legal entities

Any use of the Services on behalf of a legal entity is deemed acceptance of these ToU also for this legal entity. By using the Services or by creating an Account (art. 2.4 ToU) on behalf of a legal entity, you confirm that you are duly authorized to do so and have the capacity to bind this legal entity. In this case, these ToU apply to you and your organization (both referred to as "you" in this document).

### 2.3. Equipment

You are responsible for procuring at your expenses the equipment and software (computer, software, telecommunication means, etc.) required to access the Services, and for the payment of any costs incurred through their use. We reserve the right to specify from

time to time minimal technical requirements for accessing the Services.

### 2.4. Account

Certain features of the Solutions are only available to users having created a personal account (the **Account**) and being logged-in to their Account. To set up an Account, you must (i) provide this information required during the registration process (ii) accept the ToU and (iii) have your account be validated by us.

Accounts may only be created by or on behalf of one single person (either an individual or an entity) and shall be used only by or on behalf of that person. You are not authorized to create multiple Accounts, or to share, sell or buy an Account.

### 2.5. Additional Requirements

Additional conditions and requirements may apply to you, depending on the Solution you access and the role in which you participate to such Solution (see section 5 for the use of Biobank SQAN, section 6 for the use of NExT Platform as Biobank User, and section 7 for the use of NExT Platform as Requester).

## 3. USER CONTENT

### 3.1. Ownership

Certain Services allow Users to upload, publish or transmit Content (the **User Content**). User Content includes in particular the e-catalogues that Biobanks publish on the NExT Platform and which may be viewed and queried by users (**E-Catalogue**). Ownership in User Content you upload to the Solutions or otherwise send to us remains with you (respectively your organization).

### 3.2. License

We will only use your User Content to the extent required to provide and improve the Services, as further specified in these ToU or the Solutions' documentation. To this end, you hereby grant us a worldwide,

free of charge, transferable, assignable license, with right of sublicense, to use your User Content, including the right to adapt, copy, and publish your User Content.

### 3.3. Representations

You represent and warrant that your User Content, and more generally your use of the Services, will not:

- infringe, or cause a third party to infringe, any applicable law or regulation;
- infringe any intellectual property right, or other proprietary rights or right of publicity or privacy;
- include any false, incomplete or inaccurate information about yourself, your organization, or any information about any other individual, company or other legal entity, or be defamatory or trade libelous; or
- be inadequate, of inadequate language, obscene, immoral, or contain pornography.

### 3.4. Modification and Suppression

We reserve the right (but do not have the obligation) to adjust, refuse or remove any User Content at our sole discretion. If you have an Account, you may access, download and/or suppress your User Content via your Account. You are responsible for retaining a copy of all your User Content.

## 4. GENERAL DUTIES AND RESPONSIBILITIES OF USERS OF THE SOLUTIONS

### 4.1. Confidentiality

If you have an Account, you are responsible for the quality and confidentiality of your Account credentials and for the use that is made of your Account, including any third party's use irrespective of whether you authorized such use or not. You are fully liable for any losses and/or damages that may result from any such use. You must immediately notify us of any unauthorized access or use of your Account or any other breach of security.

### 4.2. Compliance and Restrictions

You must at all times comply with these ToU and all laws and regulations applicable to your use of the Services. Subject to mandatory law to the contrary, you are not allowed to:

- use and/or access the Services for purposes other than those provided for in these ToU;
- copy, reproduce, frame, mirror, crawl, republish, modify, create derivatives of, any part of the Solutions, the Services and/or the Content;
- access or attempt to access the source code of the Solutions, attempt to reverse compile, disassemble, reverse engineer or otherwise reduce to human-perceivable form all or any part of the Solutions or their infrastructure;
- introduce or attempt to introduce Trojan horses, time bombs or other programs designed to damage, cause adverse effects, intercept or counteract any system,

data or personal information

- access or use the Services for the purpose of building a competitive product or service or copying its features or user interface;
- gather the email addresses or other Content available through Services for purposes of spamming or for any non-personal or commercial purposes; and
- share with third parties or allow them to use all or part of the Solutions, Services or Content to which access is restricted.

Furthermore, you must comply with any additional restrictions set forth in these ToU (see in particular section 3 for User Content, and sections 5, 6 and 7 for obligations specific to the use of SQAN and the NEX T Platform).

### 4.3. Accuracy

You warrant that all information you provide in the registration process or otherwise when interacting with the Services is true and accurate. You must keep such information up to date at any time.

### 4.4. Non-compliance

Without limiting the rights otherwise provided under these ToU, in the event of non-compliance with these ToU, we reserve the right to refuse you access to the Solutions, suppress your Account (if you have one), or refuse to provide the Services.

## 5. BIOBANK SQAN I ACCESS AND USE OF BY USERS

### 5.1. Scope

The provisions of this section 5 apply (in addition to the other provisions of these ToU) to visitors and registered Users of Biobank SQAN.

### 5.2. Terms of Access

The Biobank SQAN tool to monitor, evaluate and help biobanks reach the minimal levels of SBP requirements, may be accessed and browsed by any registered or non-registered User, subject to compliance with these ToU.

However, to create an Account as a member or administrator of a biobank (each a **Biobank**) and use Biobank SQAN for the account of your Biobank, you must be and remain (i) an employee, agent or representative of a Swiss Biobank which is a member of SBP and (ii) authorized by your Biobank to access and use the Biobank SQAN for the purposes set out in these ToU (including to send us information for publication by us).

### 5.3. Quality Assessment and Label

#### a) Questionnaire

In order to obtain a quality assessment of your Biobank, you must fill in a questionnaire by providing your answers in English. Those answers shall correspond to the practices currently applied by your Biobank, and not the ones you plan to implement in the future. Whenever new practices are introduced, the information provided to the Biobank SQAN should be updated. It is advised

to review and, when necessary, update the information provided at least once a year.

If all required information is available at the time of completing the survey, filling the questionnaire will take about 2h.

b) **Evaluation**

Based on the information you provide, the Biobank SQAN will automatically calculate a score, as further described on the Biobank SQAN's documentation. This score demonstrates the compliance level of your Biobank with the different SBP requirements.

While any type of biobanks can evaluate its practices by completing the Biobank SQAN, the Governance scoring on "Ethical and Legal Requirements" was designed to evaluate human biobanks established for research purposes, whose practices fall under the scope of the Human Research Act (the HRA). The Governance scoring assessing the ethical and legal requirements (Vita Label) will thus not appear for biobanks that are not regulated by the HRA. For diagnostic and animal biobanks, guidance on the Governance aspects is also provided.

Even though we make substantial efforts to include a large panel of biobanks and biobank infrastructure practices, the Biobank SQAN might not cover some encountered situations. Please inform us if this is the case (see section 18).

c) **Label**

Depending on your score evaluation and of the result of the supplementary inspections we will perform (as detailed in our documentation), you may have the option to request one or several SBP labels. The SBP labels are protected by intellectual property rights owned by us. Their use is only permitted with our authorization, which may be revoked, and is subject to conformance with the SBP label licensing terms.

Compliance with the SBP requirements will be reviewed on a regular basis.

d) **Confidentiality**

We will treat the full answers to the questionnaire, the other non-public information we collect from you as part of the evaluation, and the dashboard and quality indicators (scoring related to Governance and Quality issues) as confidential and will not share them with third parties unless this is necessary for the performance of our contractual relationship with you or your organization, or to comply with a legal obligation. They will be securely archived at Vital-IT, Center for high-performance computing of the SIB Swiss Institute of Bioinformatics. Upon request, we will be able to conduct statistical analysis on the data obtained from you. Directory and summary of biobanks or biobank infrastructures will be publicly available. Optionally, you may also decide to appear in the BBMRI Directory, in which case information will be publicly available on such directory.

We remind you that the content and structure of our

questionnaire, of our reports, and of our evaluation processes constitute our proprietary know-how and are confidential. You may not share outside of your organization and may only use them in accordance with these ToU (including section 4.2).

## 6. NEXT PLATFORM | ACCESS AND USE BY BIOBANKS USERS

### 6.1. Scope

The provisions of this section 6 apply (in addition to the other provisions of these ToU) to Users participating to the NeXt Platform for the account of a Biobank.

### 6.2. Terms of Access

Access and use of the NeXt Platform, a tool searching samples and biobanks on a map, for the account Biobank User is restricted to Biobank Users duly registered as such in accordance with section 5.2 above.

### 6.3. E-Catalogues

Subject to your compliance with these ToU, the NeXt Platform enables you to publish an E-Catalogue online and make it available to Requesters. In this context, you must in particular:

- provide us with your datasets in the manner and format as specified on the NeXt Platform's documentation. In particular, the datasets must be pseudonymized in accordance with our requirements and you are not authorized to share with us any information permitting to identify the donors;
- specify the access restrictions applicable to your E-Catalogue, using the functionalities available on the NeXt Platform, and define which categories of Requesters may access your E-Catalogue; and
- provide us with the assistance and information which we may reasonably require for the proper operation of the NeXt Platform and the provision of the Service; and
- commits to update regularly the datasets for quality reasons.

### 6.4. Personal Data

We will process any personal data that you provide to us in your datasets to provide the Services, in accordance with our data processing terms and privacy notice, which form an integral part of these ToU. You warrant and represent that you are legally authorized to provide us with any personal data contained in your dataset, and that such personal data has been lawfully obtained and are lawfully handled to SBP in accordance with these ToU and applicable law.

### 6.5. Interactions with Requesters

The NeXt Platform allows Requesters to contact and interact with the Users of Biobanks they identified through querying the NeXt Platform. You are not authorized to share any directly identifying information about donors (such as patients or research subjects) through

the NExT Platform and Services. Access to identifying information relating to donors, and transfer of samples, shall be made outside of the NExT Platform framework and shall be subject to a separate agreement between the relevant Biobank and the Requester. We provide template documents (accessible here) which you can use in this context as a convenience to you; you are however entirely responsible for the manner your use these documents and should seek professional legal advice prior to using them.

#### 6.6. Use of E-Catalogues

You – and not us – are responsible for the manner your E-Catalogue will be used once it is published on the NExT Platform, and for compliance with all applicable laws in this context. You must carefully assess which content of your E-Catalogue is freely available online, and which content must only be made available to certain categories of Requesters (which you are responsible for selecting). Furthermore, Requesters are assigned to categories based on the information they provide, and in case this information is incorrect or incomplete, may be assigned to categories that do not correspond to their actual role. By requesting us to upload your E-Catalogue to NExT Platform, you accept and acknowledge the above risks and responsibilities. We waive any liability for the manner your E-Catalogue is used once published on the NExT Platform.

## 7. NEXT PLATFORM | ACCESS AND USE BY BIOBANKS REQUESTERS

### 7.1. Scope

The provisions of this section 7 apply (in addition to the other provisions of these ToU) to Users participating to the NExT Platform to view and query E-Catalogues (each a Requester).

### 7.2. Terms of Access

To use the NExT Platform and create an Account as Requester, you must:

- be and remain an employee, agent or representative of an organization which is active in one of the fields specified on NExT Platform;
- have a need to query E-Catalogues for legitimate purposes pertaining to your own scientific research, academic or business activities; and
- provide the information required during registration.

### 7.3. Requesters' specific duties

In addition to their other obligations specified in these ToU, Requesters must:

- use the E-Catalogues and any data available on them only for the purpose of determining and assess whether and where samples potentially suitable for a specific legitimate project exist at a participating Biobank. All other uses are strictly forbidden;

- not attempt to re-identify donors or other individuals or use the E-Catalogues and any data available on them (by themselves or in conjunction with other tools or datasets) in any other manner which could permit to partially or wholly rebuild the donors records and/or identify or single out individuals (e.g. through an excessive number of searches or too narrow searches, linking or comparison);
- not use the E-Catalogues and any data available on them on behalf of unauthorized personnel or third parties, nor permit them to access all or part of the E-Catalogues or the data available on them, nor share such data, publish it, or in any other way make it available to outside entities or individuals;
- use the NExT Platform, the Services, Content (E-Catalogues and any data available on them) and all data in accordance with all applicable law, including data protection and human research laws and ethical guidelines.
- report all irregularities observed regarding the use of the NExT Platform.

## 8. FINANCIAL TERMS

The Services are currently provided at no charge. We reserve the right to start charging fees in the future for the use of the Services. In addition, fees may apply to obtain and maintain Biobank labels, as indicated by us.

## 9. DATA PROTECTION

We have issued a privacy notice, which describes how personal data is collected through the Services and for what purposes. That privacy notice, as amended from time to time, forms an integral part of these ToU.

In addition, as part of the NExT Platform, we process personal data received from Biobanks as data processor in accordance with our data processing terms (see section 6.4).

## 10. SUPPORT, MAINTENANCE, AND AVAILABILITY

### 10.1. Support

if you encounter any problem regarding our Services, you may submit a request to our support team by email at [info@swissbiobanking.ch](mailto:info@swissbiobanking.ch) and we will revert as soon as possible.

### 10.2. Maintenance and Availability

We will continuously seek to identify and attempt to resolve problems which may negatively affect the proper functioning and availability of the Solutions. Although we will use reasonable endeavors to maintain their availability, we do not guarantee it.

## 11. INTELLECTUAL PROPERTY

### 11.1. Title to IP

Subject to Section 3.1 (**User Content**), we and our licensors own the copyright and all intellectual property rights in and to the Solutions, the Services and the Content (including for clarity any data that is accessed or downloaded from the Solutions and Services).

### 11.2. License

Subject to your compliance with these ToU and any additional applicable terms referred to on the Solutions, we grant you a non-exclusive, non-transferable, non-assignable, revocable and limited license, without the right to sublicense, to access the Solutions and the Content for your own scientific research, academic or business use, strictly in accordance with these ToU. Except as stipulated otherwise in these ToU and any limitation set forth in the Solutions' documentaion, you are expressly prohibited from using the the Services on behalf or for the benefit of any third-party. We and/or our licensors reserve all rights to the Services and the Content not expressly granted herein.

### 11.3. Third-Party Content

The Services may contain Content and/or software components developed, distributed and/or licensed by third parties (Third-Party Content). Such Third-Party Content is licensed to you under the applicable terms and conditions of the respective third-party. We will use our best efforts to identify any Third-Party Content. Nothing in these ToU restricts, limits or otherwise affects any rights or obligations that you may have, or conditions to which you may be subject, under any applicable open source licenses to any open source software which may be incorporated in and/or provided together with the Services.

### 11.4. Infringement

If you think that any portion of the Services infringe on any copyright or other intellectual property right, you may at all times contact us at [info@swissbiobanking.ch](mailto:info@swissbiobanking.ch) and we will investigate your request.

### 11.5. Feedback

Although we are always appreciative of any suggestion or idea for improving or otherwise modifying the Solutions or any Services (**Feedback**), we have not agreed to and do not agree to treat as confidential any Feedback you may provide to us. Nothing in these ToU or in the interactions between you and us will restrict our right to use, profit from, disclose, publish, keep secret, or otherwise exploit Feedback, without compensating or crediting you.

## 12. WARRANTY

### 12.1. Principle

The Solutions, the Services and the Content are provided to you "*as is*" and "*as available*". To the maximum extent permitted by applicable law, we expressly disclaim, and you waive, all warranties of any kind, whether express or implied, including, without limitation, any implied warranties of fitness for a particular purpose, quality, quiet enjoyment and non-infringement of third-party rights, or availability of the Solutions, Services or Content. In particular, we make no warranty, express or implied, commitment or representation that (i) the Solutions will meet your needs, (ii) the operation of the Solutions will be uninterrupted, secure or error-free, (iii) the information and Content available on the Solutions will be current, accurate, true or complete, (iv) the Services and results that may be obtained from the use of the Solutions will be accurate or reliable or (v) we will ensure continued compatibility of the Solutions with any third-party products, even if they were compatible at any given moment. You access and use the Solutions and the Services at your sole risk.

### 12.2. Third-party content

The Services may contain contents provided or maintained by third parties, or links to such contents. These links are provided solely as a convenience to the Users and not as an endorsement by us of such contents. We assume no responsibility or liability in relation therewith.

### 12.3. User Content

All User Content posted on, transmitted through, or linked from the Services (by you or others), including the content of the E-Catalogues, is the sole responsibility of the User from whom such User Content originates. We cannot, nor do we undertake to, control the User Content, nor any use of the Services by other Users. We do not make any representation or warranty, express or implied, as to the accuracy, timeliness, or completeness of such information and have no liability relating to it, whether arising under intellectual property, unfair competition and price indication laws, libel, privacy, obscenity, or otherwise.

### 12.4. Internet

The use of the Internet involves risks, in particular that the data transmitted may be intercepted, altered or deleted. By using the Services, you accept these risks. We decline all responsibility in this respect.

## 13. LIABILITY

### 13.1. Principle

You expressly acknowledge and agree that, to the extent permitted by law, we shall not be liable for any direct or indirect damages, including but not limited to damages arising under tort law, loss of profits, loss of use, loss of data or other intangible losses (even if we have been advised of the possibility of such damages) resulting from: (i) the use, unavailability or inability to use the Solutions or the Services, (ii) the unauthorized access to or alteration of your data, (iii) declarations or actions of any third party on or in connection with the Solutions, (iv) the Content available on the Solutions, as well as all linked websites and all documents disseminated on the Solutions, (v) any other cause relating to the Services.

### 13.2. Limitation of liability

Without prejudice to the foregoing limitations, our liability for indirect and/or consequential losses or damages is expressly excluded (including but not limited to lost profit, commercial loss, loss of turnover or profit, loss of customer base, loss of opportunity or the cost of obtaining a substitute product or service) in connection with or arising out of the non-performance or improper performance of a Service, insofar as such exclusion is permitted under applicable law.

## 14. INDEMNITY

You undertake to indemnify and hold us, our partners and employees harmless against any and all liability, loss, damage, claim, penalty, fine, costs and expenses, including but not limited to reasonable attorneys' fees, resulting from your breach of these ToU, whether or not you are at fault, in particular if you use the Services in breach of these ToU.

## 15. AMENDMENT AND SUSPENSION

### 15.1. In General

We reserve the right at any time, without having to specify any particular reason, to temporarily or permanently modify or discontinue the Solutions, any Content or any Service, with or without notice, without incurring any liability.

### 15.2. Account

If you have an Account, we may, at our sole discretion, temporarily or permanently suspend, cancel or terminate your Account, any information relating therewith, and/or your access and/or use to all or part of the Solutions, with or without notice and for any reason, including, without limitation, breach of these ToU, without incurring any liability.

## 16. MISCELLANEOUS

### 16.1. Severability clause

If any provision of these ToU is or becomes invalid, unenforceable or non-binding, this shall not affect any other provision thereof. In such event, such invalid, unenforceable or non-binding provision shall nonetheless be enforced to the fullest extent permitted under applicable law, insofar as the invalid, unenforceable or non-binding provision shall be replaced by a valid, enforceable and binding provision reflecting to the greatest extent possible the intent of the original provision.

### 16.2. Assignment

You shall not assign or transfer any of your rights or obligations under these ToU. We may assign or transfer any right or obligation or subcontract the performance of any of our obligations under these ToU to any third party at any time without your prior consent.

### 16.3. Force Majeure

We cannot be held liable for failure or delay in fulfilling our obligations due to force majeure events such as natural disasters of a substantial magnitude, wars, governmental or official acts, riots, strikes, epidemics or pandemics, or breakdowns of electrical or telecommunications networks. If such an event occurs, we will inform you immediately.

### 16.4. No waiver

16.5. Any delay or failure by SBP to apply all or part of the provisions of these ToU, regardless of the frequency and duration thereof, shall not be deemed a general waiver thereof.

## 17. APPLICABLE LAW, JURISDICTION AND VENUE

### 17.1. Applicable law

These ToU and the relationship between you and us, shall be governed by Swiss law, to the exclusion of its conflict of laws rules.

### 17.2. Jurisdiction

The competent courts at the registered office of SBP have exclusive jurisdiction to settle all disputes in connection with these ToU, subject to any mandatory forum prescribed by law. Notwithstanding the preceding, nothing in these ToU prevents us from seeking injunctive relief or any other remedy available at law in any jurisdiction in case of any infringement of our intellectual property rights.

## 18. CONTACT

For any questions or feedback regarding the Services or the ToU, you may contact us at [info@swissbiobanking.ch](mailto:info@swissbiobanking.ch).

## 19. TRANSLATIONS AMENDMENTS

### 19.1. **Translations**

The original language of these ToU, as well as all other texts throughout the Services, is English. Any translation made available is for convenience only. In case of conflicts between the original English version and any translation, the English version shall prevail.

### 19.2. **Amendments**

These ToU may be amended from time to time, in which case you will be notified by any appropriate mean (including via e-mail, or via the Services, e.g. through banners, pop-ups or other notification mechanisms). Any use of the impacted Service subsequent to this notification shall constitute acceptance of the ToU, as amended.

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